

Toward a Social Model of End-of-Life Care

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Abstract

With unprecedented numbers of people living longer and with higher expectations of how they will live out their last years, the management of end-of-life services is being brought into sharper focus. Current models of end-of-life care have originated from the hospice and palliative care movement whose expertise, developed largely with cancer patients is now being looked to for guidance in developing end of life practice for non-cancer dying patients. This paper challenges the social work profession to consider whether the hospice and palliative care model needs to be re-thought; argues that social work is well positioned to help develop a more adequate model of care; and recommends a social model that builds upon the resources and networks already surrounding individuals. The social work profession is well placed to draw upon its values, culture and experience (particularly from the service user movement) and to get involved in developing new models of end of life care. This paper argues the benefits of community engagement through network mobilisation.

Keywords: Dying, social network, compassionate community, palliative care, mobilisation, informal care.

Challenges facing end-of-life services

In developed and developing countries, with very few national exceptions, people are living longer and dying slower through degenerative rather than infectious disease (Seale, 2000, Holloway, 2009). In the UK, for example, approximately 500,000 people die every year, with the majority of deaths occurring over the age of 65. Increasing longevity and the ageing of the 'baby boomers' mean that the population of over 65s is set to rise dramatically; by 2035 the number of people over 85 years is projected to increase to 3.5 million; by 2035 the over 65s will account for 23% of the total UK population (ONS, 2012). In turn the annual number of deaths is predicted to rise to 586,000 by 2030 (NCPC, 2009).

This paper addresses the challenge that this poses for the provision of end-of-life (EOL) services, by which we mean the formal (i.e. paid) care and support for people who are approaching death. The UK General Medical Council defines EOL in terms of patients who are likely to die within 12 months. EOL includes both those with a diagnosis of a terminal, incurable illness and those who have general frailty caused by a number of conditions, long term conditions or simply old age. In 2008 the UK government published a strategy for EOL care services. Whilst such services are referred to as 'holistic', requiring input from a range of organisations, health professionals are directed to take the lead role (DH, 2008); the role of social workers or social care professionals is less clearly defined.

Dying is not always lived out as people would wish. Research published by the Dying Matters Coalition demonstrates that, when asked in good health, around 70% of Britons say they would prefer to die at home, yet around 60% of Britons die in hospital. Whilst not as many people are able to end their days at home as they would wish, approximately 95,000 do die at home (Dying Matters, 2009) and many more are at home for most of the months of sickness or frailty preceding a hospital death, so a very substantial proportion of EOL care comprises home care. Facing the EOL at home, however, is not always positive. People who are dying and their families can experience great isolation and can feel shut out of social circles and distanced from their communities (Dying Matters, 2009).

Thus there is much to be done to try to ensure that at EOL people can not only die in the place of their choice but that this is a more positive experience for both them and their families. Services around EOL care therefore need to be examined. The new Operating Framework for the NHS 2012/13, which defines quality, indicates that Commissioners should identify local measures of integrated care which will support improvement, such as patient reported experience of co-ordinated care (DH, 2011). In the UK, Primary Care Trusts (PCTs) have been charged with commissioning services and being the lead agency for EOL care provision (DH, 2009). Whilst guidance from the Department of Health recommends that this be achieved in partnership with local authorities, the leading organisation has been a health one, which would partly explain why current service models of EOL care have developed out of existing services familiar to the health service. PCTs have looked towards what they already knew for ideas and in EOL care it has been the palliative care movement where expertise is seen to lie.

Palliative care claims its approach to be 'holistic', and this paper asks what the social work profession may have to offer in understanding and operationalizing the concept of 'holistic' and in shaping services. As EOL care services are widened to include not just those with a terminal diagnosis, the role of social work within this care should become more clearly articulated. This is not the first paper to draw attention to the role that social workers should play in dying (Christ & Blacker, 2005; Black, 2007; Holloway, 2009) Although the social work profession has been 'slow to respond' (Holloway, 2009, p. 714), there has been a growing impetus in the UK towards greater involvement of social work and social care services in end of life care. The time is right for the profession to build on the government's National End of Life Care Programme which aims not only to 'support people to live and die well' but sets out a vision for an 'integrated social and health care' approach (DH, 2010a, p.11). In fact the recent guide 'The Route to Success' provides very practical support for social workers in their work with people and families at the end of life (DH, 2012). The current policy and practice framework offers a real opportunity for the social work profession to stake a claim and play its part in delivering end of life care. This paper argues that in developing new models of EOL care

that incorporate a social approach, the social work profession, with its values, culture and experience (particularly from the service user movement), is well qualified to participate in this process. Furthermore it recommends a social model that builds upon the resources and networks already surrounding individuals.

The current model of practice

The origins of the 'holistic' model of palliative care can be traced back to its early development in the 1950s by Cicely Saunders in relation to cancer care (du Boulay, 1984). In this model, the patient is seen not just as having medical and nursing needs, but as a person with physical, social, psychological and spiritual needs (Saunders, 1978). To meet these needs, a multi-disciplinary team is put together, comprising not only doctors and nurses, but also nowadays specialists in physiotherapy, occupational therapy, psychology or psychotherapy, social work, chaplaincy (recently rebranded spiritual care provision), art and music therapy, volunteer co-ordination, etc (Watson *et al.*, 2009). This shifts the relationship from a simple doctor-patient relationship to one between the team and a suffering person. This 'holistic' approach can provide attractive working conditions for doctors who wish to move beyond a narrow medical model, for nurses who wish to be on more equal terms with doctors, and for other professionals, not least social workers, who enjoy cross-professional working. The precise composition of the team varies from place to place and in the UK, not all hospices employ social workers.

In this multi-professional model, support for the patient is almost without exception provided by the professional members of a multi-disciplinary team, whether that be a community nurse teaching the family carer about lifting and handling, or a social worker advising about stress and family dynamics. There is almost no reference in the palliative care literature to main carers being supported within and by their own networks of family, friends, neighbours, faith-based networks or other non-professionals. These are quite clearly not defined as part of 'the team', and even the main carer is seen not so much as part of the team, but as the recipient of services from the team. The team often supports the patient's main family carer, but the international palliative care literature on supporting carers almost exclusively focuses on how formal services can support carers, and ignores naturally existing support networks (Hudson & Payne, 2009). Recent authoritative reviews of research (Hudson *et al.*, 2010) and an international task force on family carers (Payne *et al.*, 2010) adopt this service delivery focus on a multi-disciplinary team delivering support to patient and carer who are regarded as having complex bundles of needs. We argue that this model, with its origins in the hospice movement now being developed into more general EOL care services, needs to be adapted to be truly 'holistic' so that people are seen as fully social beings living, dying and caring within naturally occurring social networks, not just as bundles of needs to be met by professionals (Author's own, 1985).

Critique

Two issues with this model need to be highlighted and examined before it is developed further. The first, which has been noted for some decades, is that the holistic hospice model of EOL care is based upon cancer care and represents a Rolls Royce service provided to a few (Clark, 1993). Resources are unlikely to be available to expand it to everyone requiring services at this stage especially if they are suffering from diseases with less clear trajectories than cancer .

The second issue we highlight is that the multi-professional model can both empower, and disempower, people at the EOL and those family and friends who care for them. Clearly, hospice and palliative care has empowered many people to face their own dying, and empowered families to look after them, often at home. A holistic approach can humanise and to a considerable extent demedicalise dying, many professionals in hospice and palliative care want to empower dying people and their families and many patients and their families appreciate this. At the same time, however, this approach subtly, and inherently, disempowers patients and families. It carries the clear message that dying is complex and requires skilled, multi-professional support. In the very process of partially demedicalising dying, it further professionalises it. Thirty years ago, Arney and Bergen (1984) showed how the humanisation of medicine led to greater medical power, and now the humanising of

dying is leading to expansion by yet more and more professions. As Kellehear (2005) has put it, there is an expansion of occupational capacity instead of expanding communities' capacities to care. Indeed, the more professional expertise expands, the less likely professionals are to consider the lay expertise available in families and communities.

Building a social model of EOL care

Within social work generally, hyper-professionalised models have been challenged and where possible re-located within a social model. In the UK, the service user movement has fought hard to ensure that truly 'holistic' services are offered which widen the focus beyond medical and health needs. Just as a social model sees disability as caused by social stigma and exclusion rather than by physical limitations, so too the 'burden' of caring at EOL is a social rather than a medical issue.

We have argued above that the problem with palliative care is not that it is medicalised (for medical expertise is required), but that attempts to humanise care have served to replace medicalization with an even greater professionalisation of dying. We argue that palliative care's attempts to soften the medical model, i.e. re-locating such care within a multi-professional team, does not go far enough. Multi-professional working needs itself to be re-located within the total social network of care and support available, much or most of which may be informal. In this section, we suggest one way in which EOL health and care services might move towards that through a greater emphasis upon a social approach.

To develop a social approach, we suggest starting not with professional ideologies which presume the patient / service user to be a whole individual with a range of needs – which inevitably promotes the interests of professionals in meeting them (Authors, 1985) - but to start with seeing people at the EOL as persons embedded in, and constituted by, relationships. Recent research into well-being emphasises the importance of relationships for well-being (Camfield *et al.*, 2008; White, 2010), something well-understood in many non-western countries but submerged in western, and particularly Anglophone, societies by a discourse of individual autonomy (Hofstede, 2001) that is now shaping British palliative care's focus on patient choice, advance directives, preferred place of care, etc (Thomas & Lobo, 2011). Nevertheless, members of 'individualistic' countries such as the US (Bellah *et al.*, 1985) or the UK (Finch, 2000) actually use their individual autonomy to create a wide range of kin and other relationships. A relationship-based model of care, which sees professional work as empowering existing natural networks and providing specific services where needed, though foreign to most of the palliative care literature, has been developed for some years in several other fields: gerontology, social work, sociology and in political agendas of community empowerment. There are thus a number of precedents from which lessons can be drawn for EOL care.

Social networks and their mobilisation

The importance of social networks toward the EOL has not been entirely ignored, for gerontology has since at least the 1970s focussed not just on the client-professional dyad but on naturally occurring networks of care (Sims-Gould & Martin-Matthews, 2007). Key research conducted by Wenger in rural North Wales highlighted different network patterns (1984; 1991) and helpfully produced tools for social workers to identify and assess networks (1994a). Litwin has conducted extensive research into the social networks of elders in Israel (2006), and has also conducted some cross-national research (2009). Gerontology tends to focus on kin networks (Gubrium & Sankar, 1990), but there are exceptions such as Russell's (2004) identification of natural neighbourhood networks - though he does not consider how these networks function when the old person becomes so frail as to become housebound. Keating *et al* (2003) usefully disentangle social, support and care networks, and consider the circumstances in which some members of the social network become supporters when the old person becomes more frail, and then again how some members of the support network may come to provide more intensive care. A practical British example is Devon County Council's mentoring scheme that helps older people mobilise their networks (Devon County Council, n.d.).

There are previous examples of network mobilisation around AIDS, most clearly seen at the height of the AIDS epidemic in the Castro, San Francisco's gay district. Having to care for one another brought the community together in new ways - to get AIDS recognised, to get medical research funded and to challenge stigma. The San Francisco Bay area has ten thousand people who have at one time been a Shanti AIDS volunteer, many of whom already belonged to at least one dying person's natural social network (Shanti, n.d.). So this is an unusual, but perhaps the pre-eminent, example in the developed West of mutual EOL care fostering, rather than draining, community development and social capital (Authors, 1994).

Since the 1990s the concept of network mobilisation has been promoted, in part through the spread of Family Group Conferencing from New Zealand to many other countries (Burford & Hudson, 2000). This model has demonstrated that when implemented successfully, family members will come forward and offer support, and professionals can safely relinquish their role in the support network (Brown, 2007; Lupton & Nixon, 1999).

Given the interest already in gerontology and the experience from social work of challenging professionally dominated modes of care, this paper now presents an alternative model of EOL care that normalises dying by recognising and building upon the potential of natural networks to support families. Social network analysis has developed since the 1970s as a thriving area of practice-oriented research, social networks being a key part of a person's social capital, a concept popularised by Putnam (2000). Concerned by the erosion of social capital and the disconnection people felt from their communities, Putnam challenged US communities to find ways to increase participation and rebuild community and family networks. Key to social network analysis is Granovetter's (1973) distinction between strong and weak ties, which are useful for different purposes. Primary carers typically develop strong ties with those they care for (and attachment theory shows how important this is for the one cared for), but weak ties outside the family can be crucial in offering the primary carer access to a wide range of resources and support. Perri 6 (1997) introduces the concept of network poverty, going so far as to define social exclusion as network poverty and arguing that all social policy should be evaluated for whether it undermines or fosters vulnerable people's social networks. We are proposing something similar for EOL care.

Many older people toward the end of their life, housebound and with peers already having pre-deceased them, have very attenuated networks; some live in run-down low income housing schemes where trust of both neighbours and professionals is low; some have years ago lost touch with family. So they turn to close family (if available) and to the health and social care team.

A potentially helpful model based on empirical evidence of how networks often work, was in 1979 formulated in elder care by Cantor (1979, 1991) and recently articulated in the context of palliative care by Abel et al (2013); this envisages the individual's network as comprising concentric circles of potential care. What the person cannot do for themselves, resident kin will do. What resident kin cannot do, close family may come and do. What family cannot do, friends and neighbours may be able to do (especially tasks outside the house such as help with shopping, transport to hospital). Sociability may be provided by former work colleagues or friends. There will be certain technical tasks, most often medical and nursing, for which professional expertise will be called for, possibly leading to hospitalisation. There is considerable evidence from gerontology that this is indeed how networks function toward the EOL (Neale, 1993; Stephens & Christianson, 1986).

Thus health and social care professionals become part of the dying person's / carer's team, providing paid services where more naturally occurring unpaid forms of care run out. 'Only when members of the informal system are unavailable or can no longer absorb the burden of providing assistance do older people and their families tend to turn to formal organizations for help' (Cantor, 1991, p. 338). Often they turn for help with specific tasks, rather than for holistic care. Professionals who understand this model see their role partly as delivering specific services, but also partly as helping to empower the person's natural network.

A key question is the capacity of naturally existing networks. In the mid 1980s, this was a matter of some debate. Yoder and Leaper cautioned against over-estimating their capacity, concluding that ‘the model of the complementarity of professional services with supportive networks based on family, neighbourhood or occupational grouping was favoured as more realistic than a model of alternative provision’ (Yoder, 1985, p. 229). A network that may be able to support a carer through a few months of terminal cancer may struggle to provide support through several years of terminal dementia or Parkinsons. We therefore reject both a generic idealising of networks’ capacities to provide support *and* an out-and-out dismissal of the potential of networks to support EOL care. What matters is network assessment on an individual basis (Wenger, 1994b). It then becomes possible to target service delivery more equitably, i.e. to those who are network poor or whose networks have run out of resources. At present, however, families with plenty of social capital often know better how to access formal services and end up receiving their fair share and more (Perri 6, 1997).

We are not arguing that network mobilisation should replace professional service delivery, indeed Wenger’s network assessment would need some degree of professional involvement. But instead of seeing informal care as an addition to professional care, we seek to re-locate professional services *within* the entire range of care, informal and formal. Nor are we saying that network mobilisation is the cure-all for all the woes of caring for a dying friend or relative; money, to take just one example, can also be important (Beck Frus & Strang, 1993; Emanuel *et al.*, 2000).

Building on recent examples

Outside of the mainstream, there have been a few radical initiatives which attempt to naturalise dying through a process of de-professionalisation in which professionals empower existing support networks and offer specialist (often medical) expertise as needed. To our knowledge, the oldest is the Home Hospice project in Sydney, Australia, which, working mainly with people with terminal cancer, helps the person and their main carer to mobilise their social network. A recent report on this project (Horsfall *et al.*, 2011) highlighted some of its successes, not least that networks can grow through the act of support and continue after death, providing support in bereavement – thus reversing the process by which the burden of caring isolates the spouse, who in bereavement finds she has lost not only her spouse but some of her friends too. Though earlier Abbs (1982) had found that crises tend not to generate wider co-operative support because people turn to just one or two people for support, Horsfall *et al.* found that, with active mentoring, wider co-operation is possible. Significantly, this project arose as a community development rather than health care project, so it has proved difficult integrating its support networks with formal services. Home Hospice has been replicated in South Africa, working there through an Anglican church diocese (Manion *et al.*, 2012).

Whilst perhaps the best known projects are the neighbourhood networks in palliative care in Kerala, India, set up by a medical doctor (Kumar, 2007), it is difficult, in the absence of published evidence, to know whether their results are generalisable.

In the British Isles, at least two family mentoring projects have been developed. The Milford Care Centre in Limerick, Ireland, commenced a compassionate communities pilot project in 2011 and plans to develop a mentoring component (Kellehear, 2005). Funding was secured in 2012 for a project based at Weston Hospicecare in Somerset, England, where families are mentored to identify their social networks and the various tasks with which they need help, and to match the two (Abel *et al.*, 2011). There may well be other projects which have not advertised themselves beyond their locality, whose existence we are not aware of. It is also quite possible that individual community nurses and social workers do network mapping with families at EOL, even though this is not a formal part of service provision. And there is no research into how people themselves do, or do not, mobilise networks specifically to support EOL. There is certainly a growth in compassionate city projects, utilising a health promoting concept of palliative care (Kellehear, 1999), but these typically claim to operate at a more macrolevel of community capacity building and awareness raising rather than starting from the very bottom up, namely the dying persons networks..

Although the models outlined here provide examples of projects that have started to engage with the wider community it is not clear to what extent they have the potential to help people or carers mobilise and sustain networks of family and friends. It is too early to tell whether the project in Somerset will result in the enhancement of social networks or whether the end result will be a change of role, status or presence of professionals in the planning and decision-making process.

Challenges and opportunities for social work

We recognise and acknowledge several barriers to network mobilisation. Social capital comprises not only social networks but also trust and norms, such as reciprocity, which are crucial to network mobilisation (Putnam, 2000). There is a considerable research literature on norms of reciprocity and the importance of being able to reciprocate (Keating *et al.*, 2003). When a person becomes too frail or ill to reciprocate over an extended period, however, it is not known when or why friends and neighbours will continue to offer support. Just as palliative care developed its concepts and practices through cancer care, so EOL network mobilisation projects have tended to work with people with cancer; whether and how they might work for people with more uncertain and/or potentially longer disease trajectories (such as frail old age and dementia) requires innovative projects and good research.

Privacy and a martyr complex can be barriers to network mobilisation. Main carers may not wish to burden others with supporting them – the ‘caring is a burden’ script is so dominant in the UK that carers may feel that asking someone to support them in even a minor way would be a burden for the supporter, despite research evidence that support network membership provides many benefits for supporters. Other carers may feel it a burden to have to co-ordinate the support network, and that it is easier to do all of the caring themselves. When there is no main carer, the sick person may well struggle to co-ordinate their own helpers. Brown (2010) has pointed to reasons why innovation in social work can fail. Here we identify several. Service delivery clearly has a major role to play, but there is a danger that its ethos will creep back in to where we have identified it is not appropriate. Firstly, in relation to language. Not least because of the contribution of the service user movement to reforming social work (Beresford & Croft 2011), it is now very hard for social workers to call the people they work with anything other than ‘service users’. Just as doctors find it challenging to think of their patients as persons who have a life outside being a patient, so social workers may find it challenging to think of service users as persons who have a life outside being a service user – and to see that such ‘outside lives’ and the social networks that constitute them may be crucial to healing and caring. There might be the evidence that this is beginning to shift as the latest guidance from the NHS in England refers to those requiring social work services as people rather than service users (DH, 2012).

Secondly, professionals are often scared to cede control, and support from social networks is neither as linear nor as predictable as delivery of a service by professional A to user B (Rowson *et al.*, 2010). Research into the implementation of Family Group Conferencing demonstrated that professional resistance was high due to the perception that mobilising network members to play a greater role in providing care meant handing over power and control to non-professionals (Brown, 2007). Thirdly, there is the question as to whether the state can encourage civil society, active citizens in general, and neighbourliness in particular? Is it possible to re-define and re-draw the boundaries between professionals, the family, citizens and the state?

Fourthly, there may be cultural barriers that hinder this type of approach. Natural network mobilisation may be culturally problematic, so we are not advocating a ‘one size fits all’ solution. What Trägår (2007) terms ‘the Swedish theory of love’ entails high trust in the state, a willingness to pay high taxes in return for state-funded services, including paid compassionate care leave (Leadbeater & Garber, 2010), and rather little contact with neighbours. The Chinese notion of filial piety makes it children’s (not professionals’ or neighbours’) duty to care for older people (Stajduhar, 2011). Finally, a Russian doctor informally told us that in Russia and some other ex-Soviet countries neighbourly and other solidarities were destroyed in favour of the party, leaving today many terminally ill people very isolated.

Finally, the challenge for social work is how to take this forward. Social workers have a range of skills that are directly transferable and relevant to the EOL setting. Expertise in communication, family dynamics, promotion of choice, empowerment and advocacy, whilst managing individual risk leave them exceptionally well placed to enable people at EOL to mobilise their social support networks. Mentoring network mobilisation uses skills such as social network analysis that social workers could receive more training in and is based on a philosophy of empowerment and user control that they believe in.

A way forward

Recent initiatives, including policy frameworks demonstrate the opportunities to take forward the type of social network approach being promoted here. The UK's *Think Local Act Personal* agenda has as one of its main themes the development of service users' and carers' social capital, not least in the areas of disability and old age, though we have yet to find an example of this specifically in an end of life context. Moving from social services to the NHS, its End of Life Care Strategy has twelve key areas (DH, 2010a). One is 'coordination of care', but it is clear this refers to (very much needed) co-ordination of care by and within formal agencies, not (also needed) co-ordination of formal and informal care. Another key area in the strategy is 'Involving and Supporting Carers' which can entail Carer's Assessments. Yet the relevant documents focus on support for carers by formal agencies, not support by carers' own informal support networks. There is no mention here or in the more specific End of Life Social Care Framework (DH, 2010a), of supporting network assessment, as suggested in earlier decades by Wenger and Perri 6 (1994; 1997). The *Social Care Framework* Objective No. 9 aims to 'Promote supportive communities through engagement with a wide range of community services' (DH, 2010a, p. 5). A supportive community however, comprises informal networks as well as formal services, however local or community based, and it requires a more explicit objective to engage formal services with such networks. As we have noted, such engagement poses a challenge, not least in how to integrate and build informal social capital with formal services but in such a way as not to professionalize the community.

The few EOL projects that specifically mobilise carers' existing informal networks that we know of have in fact been initiated, not from the social care sector or by social workers, but by doctors. Does this absence of social care leadership or even input into such initiatives reflect their comparative lack of power within a medically dominated field or is it that mobilisation projects remind social workers of 1970s community development activity that is no longer in favour? Either way, network mobilisation is beginning to be discussed in palliative care journals and conferences at precisely the time that social care policies are beginning to point in a similar direction. Thus the time is right for social workers to contribute their expertise and experience, of what does and does not work.

How social workers are trained must be addressed. If social workers are trained to work across the life-span then this needs to start at a basic level making EOL care a compulsory component of the curriculum. Whilst 'loss' and developing 'networks' are already recognised in the new Professional Capabilities Framework for England (TCSW, 2012), social work educators need to identify specific pedagogies that would help students to think about ways in which networks could be mobilised, particularly around EOL care.

Secondly, the research agenda needs to identify this as an important area to address. Considerable research into professional care at EOL has been conducted, but this needs to be complemented by research into how naturally occurring networks do or do not support care – both in the community and in residential or institutional settings.

Third, at a national level, the drive in the UK towards greater integration in the delivery of health and social care services and the Transforming Community Services Agenda (DH, 2010b) provide a timely opportunity for social work to move into areas that have traditionally been viewed as a medical domain. In such multidisciplinary teams one way forward might be to adapt Whiting's idea of using

individuals as champions in a team to promote a specific issue (see Holloway and Moss, 2012), which in this example could be the enhancement of community networks.

The time is right for the profession to start to play a greater role in shaping end of life services. Although EOL services have to-date been shaped largely by the medical profession it is not too late for them to be influenced more by the values, skills and competencies that are central to social work (Beresford et al., 2007; Werner et al.2004).

Conclusion

As growing numbers of older people bring the need for end-of-life services into sharper focus, how service delivery promotes or undermines informal care and support becomes critical. Drawing upon recent examples from around the world of network mobilisation in EOL and elder care, we argue for the potential of the social work profession to participate in building and improving on current models drawn from palliative care. Whilst not easy, the benefits of drawing in and mobilising wider family, friends and members of the person's community to support them are obvious. Such models look to re-define relationships between professionals, family, community and the state. Recognising the potential of informal support networks could help to naturalise dying at the same time as offering better support to family members so they are less isolated, targeting professional support more effectively and more equitably, and enabling more people to exercise their choice to die at home.

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